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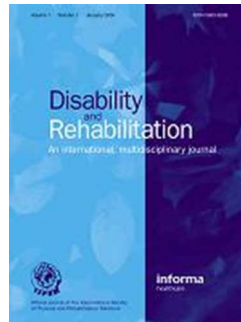
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**Trajectories of need: Understanding patients' use of support during the journey through knee replacement**

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Trajectories of need: Understanding patients’ use of support during the journey through knee replacement

Abstract

*Purpose:* To explore how the process of undergoing and recovering from knee replacement surgery alters patients’ experiences and use of their support networks.

*Methods:* Ten patients having knee replacement surgery for osteoarthritis were invited to take part in in-depth interviews prior to surgery and two-four weeks, six and 12 months postoperatively.

Transcripts were analysed using ~~i~~Interpretative ~~p~~Phenomenological ~~A~~analysis.

*Results:* Three superordinate themes were identified: (1) Relationships with health professionals over the knee replacement journey; (2) Implications for informal relationships and support networks and (3) Providing support to others.

*Conclusions:* Transformation from a person with osteoarthritis to someone recovering from a surgical intervention can lead to alterations in the source, type and level of support people receive from others, and can also change the assistance that they themselves are able to offer. Findings highlight the value of the concept of interdependence to our understanding of participants’ experiences. Activity undertaken by informal support networks assists participants to cope with the consequences of osteoarthritis and surgery, and fills in the gap when more formal support is lacking.

However, it is essential that provision of care is individually tailored and that formal support is adequate at times when informal support networks are unavailable.

## Introduction

Osteoarthritis is one of the most common long-term conditions, estimated to affect a third of people aged over 45 years in the United Kingdom (UK) [1]. Pain and stiffness in a person's joints, including knees, are common features of osteoarthritis [2]. Osteoarthritis of the knee can have considerable consequences for daily life, including detrimental impact on social life, sleep, activity levels and overall quality of life [3-5]. Strategies recommended for management of knee osteoarthritis include exercise, weight loss and manual therapy options as well as analgesic medication. If these are not sufficiently effective in enhancing function and relieving pain then knee replacement surgery may be considered [6]. Knee replacement is a major operation that involves surgical removal of an affected joint, and its replacement with an artificial prosthesis made from metal and plastic.

Knee replacement has become a common procedure in developed countries. In the UK over 676,000 primary knee replacement procedures took place in England, Wales and Northern Ireland between 2003 and 2013 [7]. Numbers of joint replacement operations undertaken, including knee replacements, are increasing globally [8-10] and with an ageing population, demand is predicted to rise [11]. People who have had a knee replacement need a period of care and rehabilitation after the operation [12], and healthcare systems vary in their rehabilitation practices [13, 14]. In the UK's National Health Service (NHS) many patients experience a short hospital stay, often returning home three to four days after their joint replacement [15, 16].

Osteoarthritis and its treatment present challenges to everyday life and bring about changes in support arrangements. Those living with osteoarthritis may engage with formal support in order to help them cope with pain and functional limitations associated with the condition. This might include input from social services and contact with health professionals, including surgeons, nursing staff, and physiotherapists [17]. Family and friends may assist with everyday activities, including help

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3 around the home [18, 19]. Although this can mean that people with osteoarthritis feel that they are  
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5 a burden on others [20, 21] this support from family and friends has been described as valuable [21],  
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7 with positive implications for mental and physical health [22, 23]. Once a decision is made to have  
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9 surgery, social support continues and formal services such as outpatient appointments and  
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11 education sessions may help people to prepare for the operation. However, people with  
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13 osteoarthritis who are waiting for joint replacement receive little active management and support  
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15 for their osteoarthritis at this time [19].  
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20 In the NHS patients tend to be admitted to hospital on the day of their operation, which is usually  
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22 performed under general or spinal anaesthetic or a combination of the two. After surgery patients  
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24 spend some time in the recovery room before they move to the orthopaedic wards where nursing  
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26 staff and physiotherapists play a significant role in encouraging patients to get up and walk as soon  
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28 as possible [24]. In the weeks after surgery, patients who have had a knee replacement may  
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30 experience post-surgical pain, impaired mobility and novel restrictions that affect daily life (e.g.  
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32 unable to drive). At this time, there may be little contact with health professionals [25] and family  
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34 are particularly important in provision of support, including personal care [12, 25]. The value of this  
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36 type of support is well documented [25-27] but can also evoke mixed reactions including gratitude  
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38 and frustration towards family, feelings of isolation, and concern about placing burden on others  
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40 [12, 28, 29].  
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46 Throughout the experience of osteoarthritis, treatment, surgery and recovery, interaction with  
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48 others, including support, takes place but is not necessarily stable or continuous. This is highlighted  
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50 in a study with people who had hip replacement surgery, in which it is argued that people  
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52 experience decreasing independence before surgery and increasing independence afterwards [26].  
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54 Independence may have positive connotations of 'freedom of choice and autonomy' [30], be highly  
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56 regarded [31, 32] and upheld as an indicator of healthy ageing [33]. Conversely, dependence may  
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connote negative aspects of ageing [30]. However, independence and dependence are blunt instruments through which to understand long-term conditions, social and formal support, and recovery from treatment. Instead, we need to consider that the majority of people live within social, political and economic contexts and 'within complex webs' of shared dependence [34]. This interdependence is evident in the concept of 'linked lives' proposed by Elder [35]. In linked lives people are interdependent, reciprocal connection occurs on different levels, and relationships have the potential both to support and control an individual's behaviour. Therefore it may be possible to further our understanding of the human experience of health and healthcare through examination of the experience of shared dependence (i.e. interdependence) and reciprocity [33, 36]. This concern is in keeping with the epistemological underpinning of our study, phenomenology, with its foundation in understanding human experiences and how people gain knowledge of the world around them [37]. Phenomenology originated from the ideas of Edmund Husserl in the early 20th century [38], who rejected the idea that empirical science is the basis for attaining an understanding of the world and instead emphasised the salience of the life world or lived experience [39].

A phenomenological lens can help to illuminate the humanness that is intrinsic to the changing illness experience ~~Both that is brought about both by~~ -living with, and undergoing surgical treatment for osteoarthritis. It offers a means to explore, and gain a deeper understanding of, how the disability and restrictions imposed by this experience change an individual's perception of their social world and need to depend on others. ~~can result in disability and restrictions that can alter a person's need to depend on others.~~ Recent work has already provided us with some understanding of the function of support for people living with osteoarthritis. Insights into the experiences of support around the time of joint replacement have also been generated from the retrospective accounts of participants who have undergone and recovered from surgery [19, 21, 25, 26]. However, this work has not addressed how people's relationships with others alter as they move from

disability, through to postoperative recovery and to functional independence; and the complexity of their social networks (i.e. who they rely on) during this time. Understanding these elements of recovery, with particular attention to the detail and subjectivities of the lived experience, provides the basis for the future development of interventions to optimise outcome after surgery. Given that people recovering from surgery are embedded in social relationships with people who provide support, understanding how this changes over time means that interventions can seek to include or involve those people as and when it may be most appropriate. Using inductive qualitative methods, our study aimed to explore how the process of undergoing and recovering from knee replacement surgery alters patient's lived experiences and use of their support networks.

**Methods**

*Study design*

The study was a longitudinal qualitative interview study with patients undergoing total knee replacement surgery for osteoarthritis. In-depth interviews were conducted with patients prior to surgery and between two and four weeks, six and 12 months after their operation. We used Interpretative Phenomenological Analysis (IPA), a well-established approach to qualitative research [40], that has been employed successfully in previous work involving people living both with osteoarthritis and those undergoing orthopaedic surgery [12, 41]. to explore participants' lived experiences and how they make sense of them [37, 38]. The dual epistemological underpinnings of this approach are phenomenology and hermeneutic inquiry. IPA itself is phenomenological in that it is concerned with the premise of 'attending to the way things appear to us in experience': how individuals perceive and provide accounts of objects and events (Smith and Eatough, 2006, p.324) [42]. Ultimately, as a method, IPA attempts to provide a detailed exploration of participants' lived experiences and how they make sense of their personal and social world. A key concern is with the

meanings that experiences hold for individuals. However, IPA also acknowledges that the researcher plays a central, significant and dynamic role in making sense of that personal experience. Therefore this method has a strong connection with the interpretative or hermeneutic tradition [40, 42]. Smith and Osborn (2004) suggest that IPA is a particularly appropriate method when a researcher is interested in learning about 'process and change' (p.231) [43]. Using IPA will therefore enable the in-depth individualised examination of the process of change and adjustment over time as patients undergo and recover from knee replacement surgery. Smith and Eatough (2006) highlight the fact that studies employing IPA are usually concerned with 'big issues, issues of significant consequence for the participant either on an ongoing basis or at a critical juncture in her or his life' (p.327) [42]. Living with a debilitating condition such as osteoarthritis, and undergoing and recovering from major surgery, can be perceived as a big issue appropriate for examination with IPA.

#### *Sampling and recruitment*

As the study was concerned with the process of undergoing and recovering from knee replacement surgery, potential participants were individuals who were waiting to undergo this elective procedure. Potential participants were approached within a large UK NHS hospital where a high number of knee replacements take place annually. Locating the research at this hospital enabled the study to include sufficient participants, and a diverse sample (from across a large geographical area, for example). Study invitation packs were mailed to 68 patients listed to undergo total knee replacement at a single NHS hospital between February and November 2011. The hospital conducts a large number of knee replacement operations, providing treatment to patients from across a region. Of those who returned a reply slip (n=17), we purposefully identified a sample of men and women, who were a range of ages. WW contacted 12 potential participants and of them 10 agreed to take part in an initial interview. The remaining two were no longer eligible to take part. One had been recruited into an alternative study that precluded their inclusion and another had had their



operation date brought forward which meant that there was insufficient time to undertake an initial interview. These 10 patients reflect the original sample of 68 in terms of age and gender. Small sample sizes are typical in IPA studies, with many having samples of 5-10 participants [40]. This is in part because during the process of analysis ‘subtle inflections of meaning’ can potentially become lost if the data set is too large [39,44]. We considered our sample size of 10 appropriate to enable us to undertake a ‘detailed, nuanced analysis’ which would facilitate an in-depth understanding of each participants’ lived experience [37,40, 45-49]. All participants provided their written, informed consent to take part immediately prior to the first interview. The researchers (WW and XX) also sought participants’ verbal agreement to ongoing participation before each follow-up interview. Demographic information about the 10 participants (six men and four women, ages 61-78 years) is displayed in table 1. All names are pseudonyms.

***[Insert table 1. Participant demographics]***

*Data collection*

In-depth semi-structured interviews were conducted with all 10 participants after they had seen a hospital consultant and were placed on the waiting list for knee replacement. Follow-up interviews were carried out with 8 of the 10 participants at each of the three follow-up points. Two participants did not take part in postoperative interviews, one because he chose not to have surgery and one because the date of her surgery moved beyond the time constraints of this study. Preoperative interviews, which lasted between 74 – 102 minutes, took place at participants’ preferred location: either in their own homes (n=7) or on University premises (n=3). The first author (WW) carried out all preoperative interviews. Postoperative interviews, which lasted from 40-84 minutes were undertaken by either WW or XX, who worked between them and with other members of the study team to ensure consistency of approach. These interviews and largely took place over the telephone, other than when a participant requested a face-to-face interview in their own home

(n=1). The first postoperative interviews took place between two and four weeks after surgery so that participants were able to recall their time in hospital but had also had sufficient time since their operation to allow for some postoperative recovery. The time window enabled some flexibility so that interviews could take place at the convenience of participants. Further interviews took place at six and twelve months as key points when recovery was likely to be underway or relatively complete.

Interview questions were guided by topic guides developed by WW, YY and ZZ and were initially informed by existing literature and through discussion with patient representatives. We also used the findings of early interviews to help us further refine the topic guides.~~Interview questions were guided by topic guides, informed by existing literature and through discussion with patient representatives.~~ Core qQuestions aimed to elicit participants' experiences of preparing for, undergoing and recovering from surgery. The core topics covered included: pain and function [3, 4, 21, 46]; support whilst preparing for/recovering from surgery [17-19]; hopes for, and knowledge of, surgery and recovery [25, 47]; and experiences of rehabilitation and recovery [15, 20, 48]. Use of topic guides helped to ensure consistent issues were addressed across participants, but we used open-ended questions and detailed probing to encourage participants to talk about their experiences and to tell their story in their own words, in keeping with methods of IPA [44,49]. This enabled generation of rich data and exploration of issues that emerged as important to each individual. With consent of participants, interviews were audio-recorded and participants also provided their consent to the publication of anonymised quotations. Research ethics approval for this study was provided by [name removed for peer review].

### *Data analysis*

Audio-recordings were transcribed verbatim, checked for accuracy and anonymised. Using IPA, we started with the detailed examination of case studies. This involved reading the preoperative interview transcript from the first participant several times. During initial readings we made notes on

the transcript of important and interesting aspects of the data and developed these preliminary notes into more explicit phrases and themes as we became more familiar with the data. We then aimed to make connections between these ideas in order to establish superordinate themes for the case; again returning to the transcript to check them against the data. The transcript of the first interview was put to one side and the transcript from the subsequent interview with that participant was then analysed in the same way as the first. This pattern was repeated until all transcripts for the case had been analysed. It was at this point that an attempt was made to identify patterns between the themes from different time points, with the aim of establishing the superordinate themes for the complete case. Once a table of superordinate themes had been compiled for a case we began the analysis process for the next participant. Once the process was completed for each case we aimed to identify patterns between cases with the key objective of formulating a list of superordinate themes for the complete group. We then ‘transformed’ the superordinate themes into a narrative account with the aim of drawing out the patterns in participants’ experiences; discovering the similarities and differences in their stories [4250]. Taking this approach we were able to illuminate patients’ lived experiences and their process of preparing for, undergoing and recovering from surgery. In particular it enabled us to discover and capture the meaning that alterations to social support systems had for patients as they navigated this lived experience.

During the process of analysis we remained mindful of the principle, as suggested by Smith et al (1999), that themes should not be chosen only on how often they appear in accounts, but rather, should be influenced by additional factors. These factors include how well passages exemplify themes and the way in which the theme provides illumination of the account. We also worked to immerse ourselves in the data as much as possible during analysis and embraced the flexibility of IPA that allows unanticipated ideas and themes to emerge concerning participants’ lived experience during analysis [3740]. During analysis and while writing the manuscript, we were mindful of the idea that a ‘good IPA study’ narrative will allow the reader to find out something about both the

salient generic themes in the analysis, and also gain an insight into the 'narrative lifeworld' the world as lived, of each of the participants [3842].

WW undertook analysis of the data and other members of the research team (YY and ZZ) commented on interpretations made during the process of analysis and within the drafts and final accounts provided. Situating results and interpretations within current literature, comparing findings with existing work, and triangulating participants' experiences during analysis, all serve to increase the credibility of the findings.

## Results

We were interested in exploring participants' experiences of support during their journey through knee replacement surgery. To achieve this we explored interview transcripts at all time-points (before surgery, two-four weeks, six and twelve month's post-surgery) together to provide as complete a picture as possible about the journey through knee replacement. From our analysis, we identified three superordinate themes that relate to dependence and interdependence: (1) Relationships with health professionals over the knee replacement journey; (2) Implications for informal relationships and support networks and (3) Providing support to others.

### Theme 1. Relationships with health professionals over the knee replacement journey

#### 1a. 'I've got faith in him': trust and confidence in the surgical team

Participants explained how the pain and impaired mobility they increasingly faced before surgery meant that they felt the need to rely on medical opinion and expertise, and that surgery was an inevitable need rather than a choice.

*It's not like having cosmetic surgery. I don't have to have it done, I got to have it done to get, to keep moving otherwise I'm gonna seize up. I'll get to the stage where I won't be able to walk at all. Practically a cripple. (Mr Ings, 1)*

There was considerable 'faith' (Mrs French) and 'total trust' (Mrs Evans) in surgical teams. This was rooted in previous positive encounters in consultations as well as experiences (their own and others) of successful outcomes after other types of surgery. For instance, Mr Jackson's confidence in his surgeon's ability was enhanced because he thought that his brother had a good outcome after surgery performed by the same, 'experienced', surgeon. Accounts however also indicated that participants' trust was tempered by recognition that surgeons 'are only human' and that outcome was not guaranteed.

*he [has] done my brother's leg, both legs, about six years before me, and he's had – you know, brilliant. I asked for him. And he's been there for a long time as well, he's not a new chap. (Mr Jackson, 3)*

*all these Consultants they're fantastic guys but they can't guarantee anything 100%. It's just common sense isn't it? They do the best they can but you don't know whether, you know, how good your op's going to be. No two people are the same so, you know. You just keep your fingers crossed. (Mr Clark, 1)*

Alongside awareness that outcome was not guaranteed, participants were also aware that surgery entailed considerable risks. They expressed a sense of vulnerability that focused on relinquishing control to the surgical team when under general anaesthetic in the operating theatre.

*So every time you have an operation you're putting yourself at risk. Especially with a big operation and that side of it always, I watch too much Holby City. (Mr Cook, 1)*

However, after surgery, even if complications occurred, participants were still confident in the surgical team. For instance, Mr Armstrong retained faith in his surgeon despite a setback when in the operating theatre, this may have related to the surgeon taking responsibility and providing a solution.

*A little bit of the cement has squeezed out through the joint and it was a slither of it and they could see it on the x-ray and it was inside the knee still. ... [Surgeon] his words were "I'm taking the responsibility, I'll be doing it" ... [Surgeon] gives a lot of confidence to you with what he's doing. He knows what he's doing and he took responsibility and he said he would put it right and that's what's happened. (Mr Armstrong, 2)*

#### 1b. Contact with secondary care team

After undergoing surgery, participants' contact with secondary care health professionals shifted from the surgical team to a team of nurses, physiotherapists and auxiliaries. Relationships with health professionals at this time subtly changed: participants wanted health professionals to provide support and guidance rather than the total control that had been the expectation of surgical teams. Although experiences were underpinned by a sense of frustration, participants' accounts indicated willingness to depend on support from staff while recovering in hospital (e.g. for self-care) as there

was little alternative. The perception that staff were ‘caring’ may have also served to reduce resistance to relying on others during this time for some participants.

*They were caring. ... they’d be available anytime um. ... the only trouble was then I wasn’t allowed to walk at all for that intervening more or less a week like, four days, five days. That was a pain that was. ... if I wanted to go to the loo I had to call for a nurse to come with a wheelchair to take me there, oh it was a right, that was the biggest chore of it that was. (Mr Armstrong, 2)*

However, some participants also thought that support with personal care and recovery during their hospital stay was lacking. Instead they felt staff would: ‘leave you to do whatever you can do’ (Mrs Biggs). This encouragement of independence was unexpected and Mr Cook described the distress he experienced when he was not offered the assistance with personal care that he felt he needed.

*I was sitting there and uh, this woman said “what you sitting there for?” I said “oh I was waiting to be washed”. She said “we expect people to wash themselves” really abruptly. I thought “you horrible woman” ... it was in front of other people, I felt really small. (Mr Cook, 2)*

Post-discharge all participants had some contact, although often infrequent, with secondary care professionals: predominantly consultants and sometimes physiotherapists. They were ‘keen’ to receive follow-up appointments and eager to obtain clinical opinion about when they should drive again, terminate use of walking aids and return to formal exercise. Interactions bolstered confidence and offered reassurance. They were also a useful forum to discuss postoperative goals and beneficial in equipping participants with knowledge and skills to enhance recovery. However, although consultations were important in informing expectations for recovery, accounts suggested that the

information provided by their medical team was not always perceived to facilitate the formulation of accurate expectations; much to Mr Ings' regret.

*I'd say, but be prepared, you will be restricted in what you can and can't do. This is not what you're told, you know, you're not told this at the time. ... I think then you should be told it is not a quick fix, it is a slow recovery. (Mr Ings, 3)*

1c. 'You were sort of cut adrift': Unmet support needs during the recovery process

Accounts highlighted the detrimental implications of unmet support needs during the recovery process. At time point two Mrs French expressed irritation that she had not received a physiotherapy outpatient's appointment, despite being told in hospital that everything was in place for her to receive this service. Instead she was left to chase this contact, something that contributed to the stress of a 'difficult few weeks'.

*I rang them week before last. ... he [physiotherapist] said "Of course we are very busy at the moment, but I will be in touch with you again, but there is a two to three week wait". ... But I was quite annoyed ... I felt like saying to him well don't bother. I mean they say I can drive within six to seven weeks ... I wouldn't even of had any physio by then. ... I know everybody is very busy and you're only one of a number really aren't you, but this physio thing really that did annoy me, because they stress about you having physio and making sure you bend your knee and all this and then nobody comes. ... it don't make sense to me. (Mrs French, 2)*

Her experiences are mirrored by others, who at time point two had also not received the anticipated physiotherapy appointment. There was a sense that input from physiotherapists was often received



too late after surgery and that earlier involvement would have helped to reduce feelings of abandonment, enhanced motivation to exercise and facilitated earlier recovery. Instead, unless paying for private care, patients are reliant on waiting their turn to receive an appointment.

*After I'd got home, there was about six weeks before I saw a physiotherapist and you were sort of cut adrift there and if some assistance could be given in that short time for people I'm sure it would help a lot. (Mr Armstrong, 4)*

When physiotherapy was offered it tended to be on a short-term basis; for a few weeks. Participants disclosed at the 6 and 12 month interviews that they would have appreciated long-term support from health professionals and an 'aftercare service at the hospital'. Instead they were in a sense of limbo and did not know where or who to turn to receive support for continuing difficulties, particularly long-term postoperative pain.

*Interviewer: And was there any other support you would have liked to have received from health professionals during your recovery?*

*Mr Ings (4): Probably a little bit more either a physio, or a check-up from the physio say after, about six to eight months or something like that, just to see how it is moving and that.*

*I would have liked to have kept on going [to physiotherapy] because I was putting more and more pressure on my knee and it was bending more and more, from my perspective, but they [the physiotherapist] put their measuring tool on it and it was so tiny the difference. It wasn't worth their time. (Mr Cook, 4)*

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3 *It's a pity they haven't got like an after – an aftercare service at the hospital, whatever*  
4 *they call it, I don't know um, you know, that you could probably go up and see. 'Cos they*  
5 *were very good these physios, they know what they're doing [...] an ideal world, just to*  
6 *go and be able to phone, you know, perhaps the person – I seen a chappie in the um – I*  
7 *went to the swimming department [means hydrotherapy ... I wish I could go back and*  
8 *see him, if you see what I mean. Um 'cos he would put me on the right track perhaps.*  
9 *[...] I don't want painkillers. I want to know if there's something I could do, like some*  
10 *sort of exer – different exercises or something I don't even know about, that um – that*  
11 *everybody goes through and I don't know about it and, you know, they might be able to*  
12 *cure it or whatever. (Mr Jackson, 4)*

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27 Postoperative aftercare in the community was also seen to be lacking. After discharge from hospital  
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29 Mrs Evans, a widow who lives alone, lacked the support of a district nurse. Instead, she was left to  
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31 struggle with self-care activities, such as changing her surgical stockings, and had to implement her  
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33 own support by paying for help.  
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37 *I think that would have been helpful, somebody you know, at least every other day, just*  
38 *to make sure that you could get them [surgical stockings] on, because they are dreadful.*

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42 *(Mrs Evans, 4)*  
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47 Mrs Evans is concerned how the 'lack of backup' may affect others more 'fragile' than her or without  
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49 financial resources to seek postoperative support. She appears frustrated that her experience of the  
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51 perceptions of hospital ward staff about the availability of postoperative care in the community do  
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53 not reflect the reality, and, suggests that receiving this support could offer reassurance and reduce  
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55 isolation.  
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*If you lived on your own, you know, if you were elderly, and you couldn't afford somebody, then that would be a problem. ... especially when they keep on talking about care in the community. ....I do think that really it's no good talking about it, it's got to be there. How we provide it, I don't know. But it would be a dreadful worry for somebody.*

*(Mrs Evans, 2)*

1d. Differing perceptions of expertise: primary versus secondary care health professionals

As described in theme 1a, confidence in secondary care professionals was consistently high amongst participants. However, their trust in, and willingness to seek support from, primary health care professionals was more mixed. Perceptions of support on offer, and received, from primary care practitioners during the postoperative period was influenced by the quality and continuity of care received prior to surgery. This is illustrated by Mr Clark's description of the confidence he has in his GP, something that lends him to depend upon him during his journey through knee replacement.

*They are a seriously good crowd. So my doctor, it's been the same GP that I've been seeing for a quite a long time now ... if I felt the need to see him, he's always there for me. ... you see the same guy each time. ... he obviously gets to know you and you know vice versa. (Mr Clark, 1)*

In contrast, Mr Jackson's account indicates his dissatisfaction and frustration with the impersonal and inconsistent care and contradictory advice he received from GPs before surgery. Like others, he perceives consultations to be too short to address adequately ~~address~~ his concerns; feels guilty about taking up too much of the GP's time, and believes that GPs lack the specialist knowledge required to provide appropriate input. Consequently in the lead up to surgery he feels unable to rely on GPs to support him with effective pain management.

Interviewer: Do you feel there's anywhere you could go to get those answers?

Mr Jackson (2): Not really, I'm afraid we are very poor at the moment... we've had the same doctor for about 40 years and he retired and at this practice we got now we get a different doctor every week, they seem to be coming and going. If you go to see anybody, they don't know nothing about you. ... I had an experience with them, one doctor give me these tablets for pain killers, something I'd never tried before and then when I went back a couple of... I don't know three or four weeks later I said "Oh your colleague gave me these" and she said "He shouldn't of never give you them" and chucked them in the waste bin. I thought blimey... they can't even trust each other.... So that's put me off a bit.

This early dissatisfaction underpins Mr Jackson's postoperative experience. Six months after surgery he again chooses not to seek the advice of his GP about the pain he is experiencing; seeing little value in doing so.

## Theme 2. Implications for informal relationships and support networks

### 2a. Changes in level and type of assistance

During the preoperative period the changes in function and pain that participants experienced impacted on the level and type of assistance provided by their informal support networks. Before surgery most became increasingly reliant on family to undertake activities such as fetching groceries and household chores. With increasing pain and functional decline participants progressively turned

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3 to others to undertake the roles they traditionally assumed within a family unit or partnership. For  
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5 example, Mr Ings needed his family to help him undertake gardening activities and to carry heavy  
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7 objects. It was striking to hear a man, a manual worker who had such a solid/substantial appearance,  
8  
9 tell me this.  
10

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13  
14 *Interviewer: Have the way that your wife and your son and your daughter support*  
15  
16 *you, has that changed at all?*  
17

18 *Mr Ings (1): Yeah it has a bit. The daughter ... she helped me plant the garden yes.*  
19  
20 *She's been down this week and I said I got some cabbage plants I want*  
21  
22 *to get in. ... I clears it with the long handled tools, yeah and she*  
23  
24 *actually bends down and puts it in for me.*  
25

26  
27 *Interviewer: And is there anything else that's changed, any different ways that your*  
28  
29 *wife or your children are helping out now?*  
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31 *Mr Ings (1): Yeah, shopping. Carrying stuff, yeah quite a bit.*  
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38 However, there were individual differences in the support that participants chose, or needed, to  
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40 seek from those around them. For instance, Mr Jackson described how during the progression to  
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42 surgery, despite experiencing functional decline, he remained independent and able.  
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46 *Interviewer: Has the support that your wife or other people offer to you changed at*  
47  
48 *all over the last twelve...*  
49

50 *Mr Jackson (1): No not really because I've never asked for any. No I've never, I can still*  
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52 *do all the things I want to do just not as far or not as easily, not as well.*  
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During the immediate postoperative period, participants' reliance on those around them sharply increased. They now called on others to help them with even small practical tasks of daily living, such as carrying a drink. Undergoing surgery also led to novel changes in the roles that participants played within their relationships. This could evoke negative emotions, including despondency and helplessness. For example, when recovering from surgery Mr Cook was often looked after by his children who were 'running errands and things' and he felt that his wife was 'treating him like a baby'. The temporary change in his role within the family unit was evident.

*Interviewer: What about your wife then and the rest of your family, how have they been supporting you since you've come out of hospital?*

*Mr Cook (2): Well my wife has been working like a trooper you know. I mean, trouble is she won't let me do stuff. ... going to the shop. Um, you know getting a magazine, treating me like a baby. Um, I mean just doing extra. ... I mean I cannot drive a car so, you know, I used to do virtually all the driving. Now my wife is doing all the driving.*

This dependency for most however steeply decreased as their recovery accelerated.

*Without [name of wife] being here I would have struggled at home. It would have been very difficult. Uh, the first couple of days, just getting out to make any food for yourself or put a kettle on you know, that was an effort. Whereas now I can put the kettle on with no problems no like, you know, I'm back to normal virtually. (Mr Armstrong, 2)*

2b. 'She's always there you know when I want her': the assumption that family will help

Married participants explained that they initially turned to their spouses for assistance during the journey through knee replacement (all married participants lived with their spouses). They were usually comfortable in accepting the help they offered, a support that was implicit and unconditional.

*And she's always there you know when I want her so yeah. (Mr Clark, 1)*

After surgery, spouses assumed increased responsibility for tasks relating to everyday living and functioning and also took on additional caring responsibilities, including personal care (e.g. helping to bathe). They also played a role in medical aspects of the recovery process. For example Mr Armstrong's wife administered postoperative anti-clotting injections and Mr Clark's wife, a retired nurse, removed his stitches. Mr Clark also asked his wife for advice about pain management. He preferred to discuss medical issues with her rather than 'bothering' health professionals.

*Interviewer: And where did you have that done, having the staples out?*

*Mr Clark (3): Er now um [laughs] um my wife, [name], is a nurse. And um well she retired about a year ago. And um we thought rather than, you know, um – she knew the people in um – in the hospital, and they gave her a thing for taking them out, um she's ever so good and ever so careful, rather than go into hospital. Um she took them out at home for me.*

Although many participants appeared comfortable in accepting that their spouse was occupying a new role as carer, two felt 'awkward' and embarrassed at asking spouses to undertake duties that they felt should be provided by paid professionals. However, such aftercare services were not available to them and they were compelled to ask their spouse for help. There was a perception

amongst participants that there was an expectation that caring responsibilities should, and would, be provided within families, even if this had detrimental consequences on the dyad (e.g. spouse having health problems of their own).

*My wife who had, she has got a problem with a disc in her neck, there is no support. I was stuck in bed at that point, where I had just come out of the hospital, I couldn't lift my leg off the bed and I couldn't put my nylon stockings on, couldn't take them off, she was giving me, my wife used to work in [Hospital name], she was giving me a bed bath, which is you know, which I think is a bit wrong really. When someone is in a predicament like that. I think there should be a district nurse, just policy that they have taken them away. (Mr Cook, 4)*

### 2c. Use of extended informal support networks

When participants did not live with a spouse, participants looked outside to extended family (children, grandchildren, siblings) and friends to meet their postoperative support needs. For instance, several were the only driver in a household. As a consequence of postoperative restrictions both they and their spouse had to rely on others for lifts to fulfil a function that they could no longer, albeit temporary, undertake.

*Interviewer: What sort of things have they [friends and extended family members] been doing?*

*Mr Jackson (2): Lifts everywhere, my wife can't drive ... so to and from hospital for any appointments or to do the shopping, anything.*



Those who were widowed had to call on extended family to fulfil the roles that spouses traditionally performed; something particularly evident in the early postoperative period. As a widow, Mrs French's family and friends provided her with 'anything that she want[ed]' before surgery; something that continued during the postoperative period when she received regular visits, was provided with meals and clean laundry. Again this illustrates how the need for support from health professionals can sometimes diminish during the postoperative period when family and friends instead fulfil support needs.

*I can't say I've wanted support from the professionals, I've got very good family, they come in every day. My son has been in this morning. Um ... and they bring me a meal every day... I think I've only cooked one meal since I've been home. (Mrs French, 2)*

Mrs Evans, also a widow, received offers of support from her son and daughter-in-law, whose visits to her increased during the postoperative period. However, these were limited to the weekends. She made use of paid help such as taxi services, rather than asking for help from friends and family members as other participants did.

*I am fortunate, in the sense that actually I can take a taxi down town and a taxi back. And to get to the doctor's, um this is what I have to do as well. (Mrs Evans, 3)*

2d. 'I'm lucky': willingness to accept help

Mixed emotions were expressed about the help participants received from their social network around the perioperative period. Several viewed it positively; as 'helpful' and 'invaluable'. They felt fortunate to be 'spoilt' by friends and family who 'rallied' around them and reflected how difficult it

would be for individuals who lacked this support. They often felt minimal discomfort in depending on others and were accepting of the situation; perhaps because it was a time limited period.

*Interviewer: What sort of support have you had?*

*Mr Ings (4): Well I've been lucky like that; the wife and the kids are pretty good, you know, I've had the support of them around me. I suppose if it was somebody living on their own it might be a bit different.*

*Interviewer: Yeah, what in particular are you thinking of?*

*Mr Ings (4): Oh loneliness and getting to do things.*

Some participants who were widowed were reluctant to burden ('put others out') and call on their extended support networks; unwilling to disclose the extent of their problems to others. This could have negative consequences such as increased pain and exhaustion.

*[Name of son] and [name of daughter-in-law], that's his wife, have to come from [name of town]. You know, when they've had a full week, uh and they're both, she's as busy as he is. ... So by the time they drive down here I feel guilty because it's the only spare time they have ... I don't think it's fair to burden them. I really don't because they got their lives to lead and you know, I think somebody complaining you know. I mean they always ask and I say "I'm fine, I'm fine". (Mrs Evans, 1)*

'Valuing' their independence and the opportunity to 'carry on and look after myself, rather than have to depend on other people' (Mrs French) were key motivations to undergo surgery. Yet following their operation participants were initially forced to increase their reliance on others. A desire to return to independence underpinned early postoperative experiences and participants craved a return to self-sufficiency. Reliance was associated with ageing; something they were

attempting to halt by having a new knee joint. However undergoing surgery did ultimately enable most participants to experience increased mobility and to regain the independence they were beginning to lose by the time they had their operation: a positive outcome of having surgery.

*Interviewer: And how do you feel about the outcome?*

*Mrs Biggs (4): Oh yes, yes, I mean to have a nice straight leg, to be able to get back into a car and drive. Be independent that was, you know wonderful. ... I mean I'm a very independent person really and I, you know to rely on people is not you know, I know what being very elderly is like. [laughs] ... you can't just do things when you want to. You have to then consult with other people, ask them if they can take you places or get things for you. ... of course I had to uh you know, really be a bit uh um a bit more reliant on people until I could actually get back into um what I call my normal life.*

**Theme 3. Providing support to others**

Although not a shared experience, a striking feature in the accounts of two participants was the impact that undergoing knee replacement had on the support they provided to others, and how caring responsibilities influenced their journey through joint replacement. Mrs Biggs, a widow and sole provider of support for her mother and brother-in-law, was particularly articulate about the reliance of others on her and the impact of surgery on this. Due to her caring responsibilities, and despite limitations and pain imposed on her by osteoarthritis, she strived to maintain her role and not let others down. As a result she increasingly used her car and mobility aids to undertake everyday tasks. Undergoing surgery forced Mrs Biggs to pass over the caring responsibilities that she traditionally assumed to her sister as she was no longer at that time able to undertake them.

Keenness and determination to decrease 'burden on others' as soon as possible and to return to her original role supporting others served to drive and motivate Mrs Biggs in her recovery from the operation.

*Interviewer: Are you where you thought you'd be six months ago in terms of recovery?*

*Mrs Biggs (4) Um, yes I think I, because things moved so well after. Yeah, yeah. But I was determined any way that I wouldn't be a burden to anyone.*

*Interviewer: No, and does that make a difference do you think?*

*Mrs Biggs (4) Yes, oh yeah. ... Well for me mentally it does because of course uh, you know I feel I got a lot of responsibility here to keep the home running and I don't want uh, to feel any one else has to come in and um, you know take over from me. ...it certainly encouraged me to get going, yes, yes.*

The positive health benefits of having her knee replaced left Mrs Evans feeling that she was now able to assume a new role and offer support and care to others; something which she felt was impossible to undertake prior to surgery.

*Yesterday, we got a little local, uh, pamphlet or whatever you'd like to call it down [Town name] it was looking for volunteers actually to help families that might be in, were going through different kinds of troubles ... so I'm going to ring them. ...I wouldn't have done it twelve months ago. I wouldn't have been physically able to just go out and be confident enough to walk. (Mrs Evans, 4)*

Discussion

This study explored how undergoing knee replacement surgery impacts on patients' experiences and use of informal and formal support networks over time. Transformation from a person living with osteoarthritis to a person recovering from a surgical intervention led to alterations in the assistance participants received from others, including source, type and level. Participants accepted the need to depend on health professionals over the perioperative period and this contact usually facilitated the recovery process (e.g. offered reassurance and enhanced confidence) and ultimately helped to minimise the potential interruption of this period of rehabilitation on participants' lived experience.

Conversely, when participants wanted to, but were not offered the support of health and social professionals to aid recovery, negative consequences ensued (e.g. distress and feelings of abandonment).

Findings suggest the need for long-term follow-up and on-going advice and support from secondary care specialists, something which-that could help to limit these feelings. Interestingly, despite a high level of trust in secondary care professionals across participants, this was not the case for primary care practitioners. Nevertheless, confidence, or lack of, remained stable over time for both groups and undergoing surgery did little to alter preoperative notions. For most, progression towards surgery was marked by increasing use of informal support networks, something which-that increased further during the postoperative period and sharply decreased as participants recovered from surgery. Although participants valued their independence, and this was a key motivation to have surgery, most accepted the need to rely on family and friends. There was a sense that participants perceived themselves to have layers of support around them: spouses were called upon first for assistance and when they were unable to fulfil support needs participants would seek out extended family and friends. There was a sense of willingness to accept others' awareness of their impaired function and readiness to integrate these public and visible changes in function into their daily

experiences. Undergoing surgery also altered the support that participants were able to offer to others and caring responsibilities affected the surgical experience and recovery. Both living with OA, and undergoing knee replacement surgery, can be associated with threatened, or actual, loss in role of helper and supporter to others. However, successful surgery can equate to a reverse of these losses, and there is a reduction in interruption to lived experience.

Findings support previous literature that has documented the reliance of people with osteoarthritis on family and friends for tasks of everyday living [18, 19]. The often short hospital stay and relatively rapid discharge after knee replacement means the intensive support offered by health professionals is for a time limited period only and responsibility for rehabilitation falls mainly on the patient and their spouse, wider family or friends. After surgery, in addition to providing practical assistance and personal care, spouses sometimes provided aspects of medical care, ~~which had the potential to affect roles and relationships within a family unit.~~ There was a sense that for some dyads it was particularly during the early postoperative period that recovery from surgery had the potential to threaten and interrupt their lived experience and adversely impact on their relationship with their spouse. At times there was a need to renegotiate roles and relationships and to take on new/changed responsibilities. This adds to previous work involving patients who had undergone hip replacement surgery whose family primarily provided support to them during this period [25] and lower limb surgery whose family were described as providing unpaid care [12]. However, earlier work involving the family carers of people living with ~~long-term chronic~~ illness suggests that this group do not see themselves as 'carers'; instead the roles that they undertake are seen as natural and a part of normal family relationships [4351], and that older people living with mobility difficulties rarely describe their relationships with significant others as 'carer' and 'cared for' [4452].

Furthermore, aside from one participant, even those living alone saw themselves to have solid and willing support networks who they felt comfortable depending upon after surgery. This insight is not

in keeping with the experiences of participants who had undergone hip surgery. This group who  
talked of, although hypothetically, being ‘adamant’ that they would not be happy about returning  
home without the support of family; feeling that they would not be able to manage [28]. Our  
analytic approach, as one that helps to illuminate the diversity and variability of human experience,  
may in part explain this discrepancy. Literature has also described the negative implications of  
reliance on others over the perioperative period in relation to feelings of burden [20, 21].  
Interestingly, this emotion was only described by those participants in our sample who were  
widowed and therefore lacked the apparently implicit support of a spouse. It is possible that this  
finding may relate to Heine and colleagues’ (2004) interpretation concerning different views about  
support between older and younger patients who had undergone hip surgery. They report that  
younger participants in their study felt more of a burden on their family whereas older participants  
had a different attitude; feeling like they had already looked after their spouse previously so it was  
now their turn [28].

The notion of independence has arisen previously in work involving patients who have undergone  
orthopaedic surgery [29] and also underpinned the experiences of those involved in our study.  
Feelings concerning loss of independence were, for most, tempered by a sense of acceptance that  
dependency on others was for a discrete period. Literature suggests that independence as a key  
feature of positive ageing can mean that older people hide signs of decline and refuse care and  
support [53, 54, 45, 46]. Participants in our study were all over 60 years; however only one said that  
they hid their difficulties from family and resisted support. This is perhaps because patients, and  
indirectly their families, had been provided with sufficient information on recovery after knee  
replacement that allowed them to expect that it would be necessary to depend initially more heavily  
on others whilst recovering from major surgery. This does however suggests the limitations of this  
notion and the relevance of interdependence instead to participants’ experiences. Furthermore, the  
way in which less support from formal support networks is accompanied by additional support from

informal networks suggests a type of interdependence with the absence of one relationship being filled with another. This is an idea previously suggested in relation to interdependence of horizontal family relationships and friendships [4755]. It is also apparent that informal care can facilitate the use of formal care, for instance, both pre- and post-surgery participants were reliant on family and friends for lifts to medical appointments. Participants' discourse highlights the dynamic connections between people within their social networks in the context of health and wellbeing. It also highlights participants' flexibility towards acceptance of changes in their relationships with others, with this acceptance perhaps serving the function of preserving the normality of their lived experience.

A large body of work has established the need to consider the role and function of patients' expectations around the perioperative period [56-58]. Our work has highlighted the major role that health professionals can play in informing expectations for recovery. Findings suggest the importance of them providing accurate information to patients concerning postoperative recovery, and the need for them to check their patients understanding of this. Ultimately this may help patients to formulate accurate expectations and limit disappointment. This links to previous qualitative work which suggests that patients should have the opportunity to discuss their expectations of joint replacement in order to limit 'false optimism' [25].

Employing a longitudinal design and use of in-depth interviews facilitated a detailed exploration of participants' experiences of their support networks as they underwent and recovered from knee replacement. Through the use of IPA, we have been able to gain an insider's perspective and increase our understanding of how people electing to undergo knee replacement surgery perceive and experience their support networks as they at first prepare for, and then recover from, their operation. It is hoped that the in-depth understandings generated by inclusion of multiple patient perspectives will also have relevance for how we make sense of recovery from, and subsequently design support, for patients experiencing other types of elective surgery. This detailed exploration



has been facilitated by employing a longitudinal design, use of in-depth interviews, and fine-grained analytic processes specified by IPA. To ensure analytic rigour we engaged in several validation strategies: discussion of findings with patient representatives, reflexivity, seeking out and paying attention to negative cases and have aimed to produce stories that are 'realistic' and 'believable' so that they are an accurate portrayal of 'all the complexities that exist in real life' (Creswell, 2007, p.46) [4859].

Qualitative researchers have traditionally chosen to meet face-to-face with participants when carrying out in-depth interviews. However research in the area now indicates that the mode of interview may have little impact on the amount, character and depth of data generated during an interview [4960]. However, in light of this, we designed the study such that initial interviews took place in person to build rapport, and consider it likely that this enabled the generation of even richer data during subsequent interviews that were conducted by telephone. Although we did not have ethical approval to access information about specific characteristics of the 58 patients who did not take part in the study (for example, marital status, length of stay in hospital), we do not feel that this knowledge would have influenced our analysis or interpretations. In addition, while the focused nature of our study may mean that it is difficult to transfer our findings directly to other healthcare contexts, the depth achieved in the data described, sampling strategy and the inclusion of participants from a standard, all be it large, NHS hospital, should mean that key findings have resonance for patients in other healthcare contexts.

All participants in our study returned to their own home after a hospital stay of 3-10 days. Future research could explore the experiences of those who take a different postoperative pathway (e.g. when patients experience extended hospital stays or are not discharged to their own home).

Findings also suggest that future work could address the specific impact of age, gender (i.e. gender differences) and cohabitation status on patients' use of support networks.

In sum, we have gained novel perspectives on the trajectories of support used by patients over the journey through knee replacement for osteoarthritis. Patients rely extensively on, and value, both informal and formal support networks over the perioperative period; with use of this support peaking in the weeks following surgery. The ongoing and active role of informal support networks in helping participants cope with the consequences of osteoarthritis and surgery may reduce their need to request or arrange formal support. Although formal support is not necessarily available or accessible it is important that health and social care systems do not assume that patients have family and friends willing or able to undertake caring responsibilities. Findings highlight, from patients' own perspectives, the potential value of postoperative physiotherapy received soon after surgery and the possible role of long-term follow-up after surgery. Findings also show that missing or ill-timed support may have detrimental psychosocial consequences for patients going through joint replacement. Provision of appropriate and adequate care to patients recovering from knee replacement should consider these issues. Finally, development and evaluation of interventions for such patients, and related recommendations for practice, should recognise the importance of informal support and take steps to ensure that support is tailored to individuals and is adequate when informal support networks are not available.

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Or Peer Review

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For Peer Review

Table 1. Participant demographics

Pseudonym	Age at first interview	Gender	Co-habitation status	Length of stay in hospital
Mr Armstrong	70	Male	Lives with spouse	10 days
Mr Cook	64	Male	Lives with spouse	8 days
Mrs French	76	Female	Lives alone	10 days
Mr Ings	64	Male	Lives with spouse	5 days
Mr Jackson	68	Male	Lives with spouse	4 days
Mr Clark	65	Male	Lives with spouse	3 days
Mrs Evans	74	Female	Lives alone	6 days
Mrs Biggs	61	Female	Lives with mother and brother-in-law	4 days
Mr Ostafew	78	Male	Lives with spouse	Did not have the operation
Mrs Parker	67	Female	Lives with spouse	Unknown (operation delayed)

### Implications for rehabilitation

- Activity undertaken by informal support networks can help patients who undergo knee replacement cope with the consequences of their operation; filling the void when support from health professionals is lacking
- Contact with health professionals after surgery enhances confidence and offers reassurance; helping to facilitate the recovery process from knee replacement
- Findings highlight, from patients' own perspectives, the potential value of postoperative physiotherapy received soon after surgery and the possible role of long-term follow up
- Missing or ill-timed support from health professionals can have negative psychosocial consequences for patients going through joint replacement